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Choices for Care Evaluation Qualitative Data Analysis Final Report

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Executive Summary

The University of Massachusetts Medical School's Center for Health Policy and Research (UMMS/CHPR) was contracted by Vermont's Department of Disabilities, Aging, and Independent Living (DAIL) to gather baseline qualitative data on a set of core processes and outcomes of the Choices for Care (CFC) waiver as one part of the evaluation for the CFC waiver. The aim of collecting these data was to explore the perceptions and experiences of a variety of stakeholders of the waiver in the following areas:

- Awareness of CFC service options and settings
- Eligibility procedures
- Support to foster participant choice and preference of settings and services
- Access to CFC services
- Quality of CFC services
- Experiences with ombudsman services and
- General perceptions of CFC and recommendations for improvements

Two primary methods were employed to gather the qualitative data. CHPR conducted key informant interviews with state staff responsible for the implementation of the waiver and staff at advocacy agencies in Vermont while CHPR subcontracted the University of Vermont (UVM) to conduct focus groups and key informant interviews with CFC participants, family members and providers.¹ Specifically, CHPR interviewed a total of 22 individuals (14 state agency staff, 5 advocates and 3 providers) and UVM conducted both key informant interviews and focus groups which included 58 respondents (21 CFC provider staff members, 20 family members, and 17 CFC participants).

All key informant interviews and focus groups with the five stakeholder groups (state staff, advocates, providers, CFC participants, family members) took place between July 2007 and April 2008. Interviews were recorded by written notes and audio-taped unless the respondent asked not to be taped. CHPR and UVM staff utilized qualitative analysis software to support the process of identifying and analyzing themes. CHPR utilized ATLAS.ti and UVM used Survey Monkey to analyze data from focus groups and key informant interviews. CHPR developed the coding scheme for analysis of all interviews and documented this in a code book (see Appendix 1). Themes for the codebook were developed through consensus among evaluation staff before analysis was conducted and additional themes that emerged during the data analysis were added to the codebook. CHPR and UVM collaborated to ensure code book themes were representative of all interviews conducted by both CHPR and UVM.

¹ CHPR subcontracted with UVM to assist with this qualitative study. Data from summary reports by UVM on provider, CFC participant and family members perceptions of CFC are referenced in this report.

Below are key themes that emerged within each topic discussed in the focus groups and key informant interviews. Key themes are those themes that were found across at least 3 (of 5) stakeholder groups or were stated or emphasized by interviewees as central to CFC processes. Following each key theme are suggestions for improvement.

- ***Awareness of CFC service options and settings***

Key Theme:

- Across stakeholder groups, most respondents reported being aware of the basic CFC services, e.g., personal care and setting options such as enhanced residential care, nursing homes, and home and community services; however, across all stakeholder groups, respondents' knowledge about the newer CFC options, e.g., Flexible Choices and option to pay a spouse was comparatively less.

Suggestion for Improvement:

- Ongoing options education for both providers and participants will be crucial to improve and sustain knowledge of existing and new options and change attitudes towards home and community-based services (HCBS) as a viable option to nursing facility care.

- ***Eligibility procedures***

Key Theme:

- The financial eligibility processes were cited as the most difficult piece of the eligibility process for CFC participants by 3 of the 5 stakeholder groups, even with assistance from Department of Children and Families (DCF) staff responsible for financial eligibility determination, such as making calls on behalf of participants.

Suggestion for Improvement:

- Efforts by DAIL and DCF to make eligibility processes more user-friendly and timely for applicants will be important as CFC implementation continues.

- ***Support to foster choice and preference of settings and services***

Key Themes:

- Most CFC participants noted that their case managers were supportive in developing a plan of services. Nevertheless, in some regions of Vermont, CFC participants are not able to choose from the full range of services or settings due to shortages of HCBS workers such as personal care attendants (PCAs) and available of enhanced residential care homes (ERCs) and nursing home beds at the time of application. Responses from CFC participants also suggest that specific support for participants to self-direct was lacking.
- While it was stated that providers often strove to uphold participant preferences for services and settings under CFC, influences from

family members, physicians, and other providers are inevitable and hard to separate from participant preferences. Furthermore, participants' lack of knowledge about CFC services and settings can hamper their ability to be informed decision makers regarding preferences regarding services and settings.

Suggestions for Improvement:

- Efforts by case managers and others to continue educating participants on their service and setting options under CFC (beyond options education by LTCCCs) may help to foster participant knowledge about the waiver's options. Furthermore, support with hiring, training and firing workers for participants who self-direct would be a helpful addition to the existing fiscal intermediary services.

- ***Access to CFC services***

Key Themes:

- Respondents across stakeholder groups noted that there was a shortage of personal care and licensed nursing aide workers, particularly workers through agencies. Such shortage makes it difficult to fill approved service hours for CFC participants, especially weekend and evening hours.
- Respondents across stakeholder groups also expressed a desire for more non-medical transportation and companion services.

Suggestion for Improvement:

- Subcontracting with more providers could expand the worker pool for CFC participants.

- ***Quality of CFC services***

Key Theme:

- Respondents from most stakeholder groups noted that CFC services meet the basic personal care needs of most participants in the waiver.

Suggestion for Improvement:

- Advocates and CFC participants, in particular, noted that increases in worker pay, benefits, and education could help increase the quality of care.

- ***Experiences with HCBS ombudsman service***

Key Themes:

- Those interviewees who have had experiences with ombudsman services noted that the ombudsman service was helpful, particularly in disagreements regarding level of need or service plans.
- Ombudsman reported that outreach to participants in the community was challenging, due to ombudsman under-staffing and the geographic dispersion of HCBS participants.

Suggestion for Improvement:

- Ombudsman services for those in HCBS in CFC could improve their outreach efforts with increases in staffing and resources.

The findings presented here are those key themes stated across stakeholder groups or that were noted as being key to CFC processes during key informant interviews and focus groups. The full report contains additional themes from each stakeholder group that were not stated by all groups but that emerged as important topics during key informant interviews and focus groups. Additional challenges and improvements to CFC processes were also offered by interviewees which are noted in the body of this report as well.

I. Introduction

The University of Massachusetts Medical School's Center for Health Policy and Research (UMMS/CHPR) was contracted by Vermont's Department of Disabilities, Aging, and Independent Living (DAIL) to help DAIL better understand the experiences and perspectives of stakeholders involved in CFC to identify possible improvements to program processes. To meet this aim, CHPR conducted key informant interviews with Choices for Care (CFC) waiver implementation staff and Vermont advocates for elders and adults with disabilities. Additionally, UMMS/CHPR subcontracted with the University of Vermont (UVM) to conduct focus groups and key informant interviews with CFC providers, CFC participants and CFC participant family members. In consultation with DAIL and UVM, CHPR developed guides for the key informant interviews and focus groups appropriate for each stakeholder group (state staff, advocates, providers, CFC participants and family members). The guides covered the following topic areas:

- Awareness of the program service options and settings
- Eligibility policies and procedures
- Support to foster choice and preference of settings and services
- Access to CFC services
- Quality of CFC services
- Experiences with ombudsman services and
- General perceptions of CFC and recommendations for improvements

CHPR, DAIL and UVM drafted a core set of questions which was then tailored to each stakeholder group and its characteristics and experiences. See Appendix 1 for the core set of questions from which separate versions were developed.²

II. Methods

Selection of Study Subjects

The mechanism for selecting state staff, advocates, providers, CFC participants and family members for inclusion in the study was determined in collaboration with DAIL, CHPR and UVM staff. CHPR first independently drafted inclusion and exclusion criteria for each of the stakeholder group, followed by discussions with CFC staff. DAIL then provided suggestions for points of contact and contact information, where these were missing.

For CFC participants, inclusion criteria were individuals living in the community, including ERCs, who, at the time of recruitment, had been in the CFC waiver at least 6 months. These included CFC participants from all need

² Interview guides for all stakeholder groups are not presented in this report in the interest of keeping this report as brief as possible. Please contact CHPR for copies of individual focus group and interview guides.

groups (Highest, High and Moderate) and CFC participants self-directing their care. Participants who were excluded were those with dementia diagnoses, as persons with dementia can be often unreliable sources for self-reported data. In addition, participants residing in nursing homes at the time of recruitment were excluded because their experiences with respect to service access and quality were expected to differ substantially from HCBS participants, a challenge in keeping focus groups participants relatively homogenous. Since only a limited number of focus groups would be conducted for this study, DAIL opted to gather information from participants who would have experienced some of the newly administered HCBS processes under CFC, e.g., LTCCC options education and HCBS ombudsman service. Lastly, those admitted to nursing facilities at the time of the interviews may have conditions that would make it over burdensome to participate in interviews/focus groups. When focus group participation was low, UVM, CHPR, and DAIL agreed that CFC participants and family members could be invited via phone invitation to participate in either an in-person focus groups or phone interview. CFC participants chose the option that was more convenient for them.

Family members of both CFC participants who were interviewed or participated in a focus group were included in the study. Family members with CFC participants in various HCBS settings including ERCs, living in a family home, congregate housing in the community were included in the sample as well. Family members were not necessarily relatives of CFC participants selected for this study.

Providers were selected to provide a diversity of perspectives through their different roles and experiences with CFC participants. Care was taken to include direct care staff, supervisory staff from agencies and executive-level staff. For example, case managers and supervisors from area agencies on aging (AAAs) and home health agencies (HHAs) were included as they have direct experience with participants. Senior-level or executive-level staff from ERCs and adult day programs were included since these staff members at these entities often have direct experiences with participants. Other provider types included in interviews/focus groups were nursing home discharge planners, independent direct care providers, and those from assisted living facilities (see Table 2 for a list of providers by role and type). The inclusion of providers for this study was done in collaboration with DAIL.

A variety of advocacy groups were selected to participate. Selection included groups that represent the interests of elders, persons with disabilities, and who have a role in advocating for long-term care issues on providers and participants' behalf. Also included, were staff from the ombudsman program which advocate participants in both nursing facilities and HBCS settings (see Table 1 for a list of advocacy agencies). The inclusion of advocacy groups for this study was done in collaboration with DAIL.

In sum, it should be noted that the selection of interview and focus group participants for all groups was limited to those who could provide perspectives on some of the newer HCBS options under CFC. This decision was made after discussions with DAIL on the types of data they would find most valuable at this point in the CFC implementation. As result of the focus on newer HCBS options, this report does not address the full range of services under CFC, such as those in nursing facilities.

CHPR Interviews with State Staff and Advocates

The evaluation team at CHPR conducted 19 separate interviews with 24 individuals (14 state staff members, 5 advocates, 5 provider agency staff). (Three state staff invited three provider staff to participate in their interview as they felt it would help inform the discussion.) See Table 1 for a list of agencies and affiliations of those interviewed.

Table 1: Number of Staff at Specific State Agencies and Advocate Agencies who were Interviewed by CHPR

State Agencies or Staff Roles	Number of Staff Interviewed
Department of Children and Families	4
Long Term Care Clinical Coordinators (LTCCCs)	3
LTCCC Supervisor/Manager	2
Quality Management Unit	1
Office of Public Guardians	1
DAIL Department of Licensing and Protection	1
DAIL Independent Living Services	1
DAIL Housing and Supportive Services (HASS)	1
Subtotal	14
Advocate Agencies	Number of Staff Interviewed
Vermont Long-Term Care Ombudsman	1
Vermont Center for Independent Living/Vermont Coalition for Disability Rights	1
Disability Law Project	1
Vermont Association of Professional Caregivers	1
Vermont AARP	1
Subtotal	5
Provider Agencies	Number of Staff Interviewed
Northwestern Counseling and Support Services staff (24-hour care pilot contractor)	2
Housing Authority at a HASS site	2
AAA staff who attended with a DCF staff	1
Subtotal	5
TOTAL # OF INDIVIDUALS INTERVIEWED BY CHPR	24

Note: CHPR was referred to Northwestern Counseling and Support Services staff by the developmental disability advocates. CHPR interviewed Housing Authority staff and COA/AAA staff together alongside state agency staff.

UVM Interviews and Focus Groups with Providers, CFC Participants, and Family Members

Providers

UVM staff conducted key informant interviews or focus groups with 21 provider staff. Nineteen providers participated in one of the two focus groups held, and 2 providers were interviewed individually by phone. See Table 2 for a list of providers by their role and agency type.

Table 2: University of Vermont (UVM) Provider Focus Groups and Interviews by Role and Setting of Care

	Assisted Living Facility	Congregate Living	ERC	Adult Day Program	Private Homes	Home Health Agencies	Area Agency on Aging	PACE	Nursing Homes	Total
Case managers	1	0	1	1	0	0	1	1	0	5
LNA's	0	2	0	0	3	0	0	0	5	5*
PCA's	0	1	0	0	3	0	0	0	1	3*
Nursing Supervisors	0	0	0	0	0	1	1	0	0	2
Nurses	0	0	0	0	1	1	0	0	1	2*
Home providers	0	0	0	0	2	0	0	0	0	2
Program Directors	0	1	0	1	0	0	0	0	0	2
Total										21

* Some LNAs, PCAs and nurses provided care to CFC participants in more than one setting

Participants

Seventeen CFC participants took part in either a key informant interview or focus group. The original intent was to hold only focus groups with CFC participants; however, participants cited difficulties with transportation and their frail health as reasons they were unable to attend focus groups held in the community. Seven participants were scheduled to participate in focus groups; however, 1 focus group had a total of 3 participants, while another focus group had 2 participants. UVM consequently switched to telephone interviews and completed interviews with 12 participants.

The ages of the 17 CFC participants ranged from 29 to 94 years old. The mean age of participants interviewed was 62. (Care was taken to include both younger recipients of CFC services and older CFC participants.) Ten interviewees were women and 7 were men. Participants in all three CFC levels of need (Highest, High and Moderate) were either interviewed or attended a focus group. Respondents lived in various housing settings in the community at the time of the interviews/focus groups (as noted nursing facility participants were not included in the sample of participants for this study). Table 3 shows the number

of CFC participant interviewees by their residential setting and the individuals with whom they lived.

Family Members

Finally, UVM conducted two focus groups and key informant interviews with a total of 20 family members of CFC participants. The age range of family members was 34-89. See Table 3 for a breakdown of residential setting in which CFC participants and family members lived at the time of the interview and the individuals with whom the participant or family lived (e.g., with a spouse, or living independently). Family members reported where the CFC participant they were related to, lived in the community and with whom they lived. This information is shown in Table 3.

Table 3: CFC Participant Living Settings as reported by Participant Interviewees and Family Member Interviewees

CFC Participant Interviewees' Self-Reported Living Setting						
	Independent (Living Alone)	Staffed Setting	With Spouse	With Parent	With Child(ren)	Total
Family Home (private residence with blood relatives)	8	0	3	1	1	13
Community Home (with in-home staff support services)	1	0	0	0	0	1
ERC	0	2	0	0	0	2
Congregate Senior Living (in apartments without staff support services)	0	1	0	0	0	1
Total # of Participants interviewed by UVM						17
Living Setting of Participants as Reported by Family Member Interviewees *						
	Independent (Living Alone)	Staffed Setting	With Spouse	With Parent	With Child(ren)	Total
Family Home (Private Residence)	2	0	3	1	6	12
Community Home (with in-home services and CFC)	3	0	0	0	0	3
ERC	0	2	0	0	0	2
Congregate Senior Living (in apartments without support services other than CFC)	0	0	0	0	0	0
Nursing Home	0	3	0	0	0	3
Total # of family members interviewed by UVM						20
Total # of participants and family members interviewed by UVM						37

*Note: This table does not assume the relationship between interviewees and CFC participant.

Interview and Focus Group Methods and Analysis

The key informant interviews conducted by CHPR and UVM lasted a minimum of 30 minutes to a maximum of 90 minutes. Focus groups with participants and family members (facilitated by UVM) each lasted approximately two hours. The key informant interviews with state staff and advocates were conducted by two to three CHPR evaluation team members. One to two staff took notes while the third conducted the interview. Hand-written notes were taken and interviews were tape-recorded with the interviewee's permission as a reference to ensure accuracy of interview summaries. Each interview summary was analyzed using ATLAS.ti software. Based upon the review of all summaries, the evaluation team created a code book that contained a number of pre-determined and emergent themes for use in analysis of interview summaries utilizing ATLAS.ti. CHPR staff collaborated with UVM to learn of emergent themes from UVM key informant interviews and focus groups for inclusion in the code book. The final codebook further guided the analysis of all information collected by CHPR and UVM. (See Appendix 2 for code book).

UVM staff conducted the analysis of their key informant interviews and focus groups with providers, CFC participants, and family members using Survey Monkey software. For each focus group and interview, a summary was completed and reviewed for analysis of the data. UVM also provided summary reports to CHRP containing main themes for the provider, CFC participant and family members' interviews/focus groups.

This report integrates the UVM key informant interviews and focus groups with those from the CHPR interviews. Themes from all key informant interviews and focus groups are reported by topic area and, within each topic, by stakeholder group (state staff, advocates, providers, participants and family members). Language is used throughout the report that quantifies the themes found from interview/focus group data. Language and percentages are found in Table 4.

Table 4: Reporting Language

Reporting Language	Percentage of Respondents
Almost all	90% -100%
Most	50%-89%
Some	40%-59%
A few	20%-39%

III. Key Informant Interview and Focus Group Results

Results are described for the following topics:

- Awareness of CFC service options and settings
- Eligibility procedures
- Support to foster choice and preference of settings and services
- Access to CFC services
- Quality of CFC services
- Experiences with ombudsman services
- Other cross cutting themes that emerged during interviews/focus groups and
- General perceptions of CFC and recommendations for improvements

Awareness of CFC Service Options and Settings

Each stakeholder group was asked a set of questions about their awareness of CFC service options, settings and mechanisms through which participants are informed of CFC options. Questions included:

- Are you called upon as part of your role to explain the program to participants? (for providers, state staff)
- How would you describe the CFC program (for participants and family members)
- Based upon your experiences, how well do you think providers and participants of CFC understand the CFC services and setting options? (for staff staff)
- What do you know about the program today that you wish you knew sooner? (for participants and family members)

State Staff: Awareness of Options and Settings

Most state staff interviewed stated they were aware of the CFC levels of need, the basic service options, and settings and could explain these aspects to participants. Some reported that they have had to explain the program to participants as part of their position within the state. In cases where participants had questions for which they did not know the answers, they knew where to refer the participant for answers.

Most noted that they knew at least “some” about the options *recently added* to CFC, such as the Flexible Choices, the option to pay a spouse, and the 24-hour care. Some state staff interviewees noted that those at the state who had the most contact with participants, e.g., LTCCCs and the LTCCC supervisors, had the most knowledge of these recent additions to the CFC program. State staff without as much direct contact with participants stated that they knew “some” about these options, they knew which DAIL staff person to contact in order to get more information for themselves or for participants.

“If someone needs help I can pretty much direct them where they need to go and if I don’t know, I can find out.”

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State staff reported learning about CFC in various ways. A few state staff noted that they learned about the newer options under CFC at waiver team meetings when discussing participants who were utilizing those newer options. A few others also noted that they learned about the waiver while it was being developed from the previous HCBS waiver in Vermont while they were in other positions with the state or DAIL.

State staff interviewees shared a number of perspectives regarding participants' awareness of CFC service options and settings. There were three main factors that state staff named that affect participant knowledge of CFC services and settings. First, most state staff interviewees noted that the LTCCC's options education is a key vehicle for the dissemination of information to participants about service options and settings. Additionally, it was noted that after the initial LTCCC options education, state staff viewed it as the case manager's role to perform ongoing education with participants about the service options and settings within CFC. Some noted that they felt the options education provided an "overwhelming" amount of information for people and that it was important for case managers to continue to support the ongoing education of participants about service options and setting options of the program.

"I think it [options counseling] can be overwhelming for people initially, but it like, plants the seed for those options ... and then the case managers in their follow-ups touch on them [services and settings options] as well."

A second factor perceived by state staff affecting participant knowledge was participants' pre-conceived ideas about the service options and settings they might prefer before receiving options education. Some state staff reported that consequently, participants do not tend to take in as much information about all the other service options available because they were focusing only on what they wanted at the time of their initial options counseling.

*"Normally during the first visit the LTCCC does a clinical assessment and they do options education. What I see is that they do give options, they tell them what's available, that there are these three settings we have to offer, here are the services and here are some other options. But it's a lot of information at once. Often I see that at that point in time the family or the individual has something in mind already. So they say 'Well I don't want any of those options, I want **this** [emphasis as spoken in interview] option. I just find they become focused on what they want or what they see so I think over time and even after that initial visit it's hard for them [participants and family members] to retain or really know or keep that knowledge of those other services."*

A third factor cited by state staff as affecting participant awareness was that case manager knowledge of CFC. For example, if a particular case management agency had more experience with CFC participants, their ability to have case managers provide on-going information about CFC was better than an agency that did not have as much experience with CFC participants.

State staff interviewees were also asked about their impressions of providers' knowledge of CFC. State staff suggested that providers did know about the basic options and settings under CFC, including service options under each level of need and the setting options. However, it was noted that providers generally had less information about the features of the program added later in the implementation of the waiver, namely, the option to pay a spouse, Flexible Choices, and the 24-hour care option. A reason cited for this was that some of these options have limited availability, such as the like 24-hour care option,. Furthermore, providers may learn of newer options in the process of assisting participants with these options.

"They [providers] differ too with how much experience the different agencies have had with them [Flexible Choices and the option to pay a spouse]. You know some have had more experience with it so there is more knowledge there, whereas, some others need more assistance in learning it and working with it. So it's a work in progress."

Advocates: Awareness of Service Options and Settings

All advocates reported having at least "some" knowledge of the CFC levels of need, knowledge of many of the basic service options under CFC (e.g., PCA services, LNA services) and service setting options (e.g., nursing facilities, ERC). However, just as with some state staff, some advocates felt they did not know as much about the option to pay a spouse or the Flexible Choices service option.

"Well I'm not—I guess I'm unsure [about the Flexible Choices option]—it seems like the folks I've worked with, their case managers have been pretty good about letting them know what their options are, so I would guess they have some knowledge of that."

"I think they [the Ombudsman] know some about Flexible Choices. I mean that's something that hasn't, you know, that is sort of new and it hasn't really been promoted that widely yet."

When speaking about provider and participant knowledge of CFC, advocates also suggested that their knowledge of the newer options was lacking. One possible reason cited for this was that the information given to participants about the program during options education was not always enough to help participants make decisions about CFC services or written in a consumer-oriented way. While advocates did participate in developing materials for

consumers about CFC, they suggested that for some participants this information may not be enough to help them make decisions about services and settings.

“They [participants] might get a flyer but they didn’t really have enough information behind the flyer to help them evaluate whether the fixed plan of waiver services was better for them or whether they would benefit from Flexible Choices option, for example. So they were grappling with...and needed some assistance just to know what both meant.”

“I think the Flexible Choices works for those people [using it] ... but again some people may need some support and information to even start thinking through the best way use a flexible funding mechanism, we [Vermont] are still in the early stages of providing some options counseling and support for it [Flexible Choices].”

Providers: Awareness of Options and Settings

A few providers were extremely knowledgeable about CFC. They explained the options to many CFC participants and family members as part of their role, and they had developed a variety of strategies for explaining policies and procedures to CFC participants related to their choices.

“I say it is a menu of options that can help people choose where they want to live and how they want to receive care.”

Some providers stressed the importance of providing explanations in a way that matched the developmental and cognitive needs of the participant or potential participant. Providing information in a variety of formats, exploring their own intuitions about their needs, and making sure the participant and their family members talked with a case manager were cited by providers as ways they informed participants about options. Additionally, some providers stated that continually explaining the program on a regular basis is important since they noted participants seldom comprehended it the first few times. Providers also said they pointed out specific aspects of the program that might be a good match for the participant based on what they knew about a particular participant’s situation.

Participants: Awareness of Options and Settings

CFC participants expressed a wide range in their understanding of CFC options--from being very familiar with CFC to having only vague ideas about CFC services. Awareness of options, for both elders and younger adults with disabilities, seemed to be based primarily on an individual’s desire to be in charge of his/her life and care. For older Vermonters who participated in interviews and focus groups, prior involvement with other programs (e.g. senior living residences, Meals on Wheels, etc.) seemed related to how much they were aware of CFC options. For younger adult interviewees, a history of disability or

chronic illness was often associated with awareness of the range of options offered. Those whose clinical eligibility under CFC came on suddenly seemed more likely to have taken whatever options were suggested to them at the time they enrolled. Participants who were self-directing their care were far more aware of their options than those with surrogate-directed care or those using agency-directed care.

Most participants said they first received information about CFC from either a senior advocate (a case manager from an AAA or HHA aiding the participant) or a disability advocate (a person from the Center for Independent Living) or a friend. Those who had AAA case managers mentioned their case managers as being their main source for information. A few participants talked about how important it had been to have case managers, or friends or family members, to push them to explore options or choose options that they initially found distasteful.

“I’ve worked hard all my life and taken care of myself and my family. I hate being like this, all I can do is try to take care of myself, to get to the hospital, to do what the doctor says, to try to stay alive. I’m embarrassed and guilty to be using a government program. But it’s better than the whole burden being placed on them [family] to take care of me.”

Family Members: Awareness of Options and Settings

Some family members reported they had planned carefully with their parents, spouses, or children for long-term care needs; however, for many, the need for care came on unexpectedly due to a change in the participants care, thereby requiring family members to make new arrangements quickly.

“I suppose, in a general way, I did know there were options, but it all happened so suddenly, we had to take what we got. I’m glad we did.”

Many family members mentioned how extremely helpful the people from councils on aging (COAs) and home health agencies (HHAs) were in giving them information about CFC, but also noted that the amount of information seemed overwhelming. They stated that there was a tendency to pay attention to only the information needed to take the next step in caring for their family member. Many family members reported that they got much of their information about service options under CFC from their family member’s case manager, friends or other family members.

Family members reported having great interest in learning more about CFC. There was a fair amount of confusion about the relationship between CFC and services sometimes offered by mental health or developmental disability agencies in Vermont. It was unclear to most family members where CFC began and ended and where other supports (non-long-term care Medicaid, Life Line,

etc.) fit into their family members' care. Although the CFC participants in a few families had been in, or currently were living in, a nursing home, few viewed the nursing home setting as a CFC service.

Eligibility Processes and Procedures

All stakeholder groups were asked questions about how they perceived the financial and clinical eligibility processes and how these processes effected CFC participants and what barriers or challenges there were regarding eligibility for the CFC program.

State Staff: Eligibility Processes

Many state staff noted that they encountered issues with providers (particularly nursing facilities) who needed more information on, what some termed the “two-part” eligibility process. They reported that providers continued to need instructions on filling out both the program or “clinical” eligibility applications and financial eligibility applications in order to enroll someone in the program. State staff also noted that HCBS providers often lacked information on eligibility processes. State staff suggested that providers did not always understand that the program/clinical application was filled out first, which then led to the second application to determine Medicaid or financial eligibility. Additionally, a few state staff interviewees suggested that the co-location of the LTCCCs (who determined program/clinical eligibility) and staff at the Department of Children and Families (who determined financial eligibility) in many regions in Vermont, may confuse participants and providers regarding the application process.

“I think the biggest confusion about this collaboration [between DCF and clinical eligibility staff in the same offices] is when you say ‘application’; we think you are talking about the Medicaid application... I have to keep reminding staff that when people talk about an application to ask them which one they are talking about [the program/clinical or financial eligibility application].”

In terms of clinical eligibility some state staff noted that the questions on the Independent Living Assessment (ILA) pertaining to social supports and cueing for cognitive needs (such as for persons with dementia and psychiatric conditions) were not always accurately or fully completed. Many state staff who spoke about the assessment remarked that this was, in large part, due to the emphasis of the ILA on ADL needs.

Also with regard to the ILA, some state staff suggested that there were variations in the way case managers performed assessments and re-assessments. They noted that some less experienced case managers might not ask participants to perform tasks as part of the assessment process but rather ask them to verbally describe their functional abilities. From the point of view of

LTCCC's, this could result in inaccurate assessments, which can lead to care plans that do not match participants' true functional abilities. Another theme related to the completion of the ILA was that staff at area agencies on aging (AAAs) had a tendency to act as "advocates" when assessing participants, i.e., assess participants in such a way as to enable more service hours for a participant,

Another significant theme noted by many was that the clinical eligibility process was also seen by many as a more efficient process than that of the financial eligibility process. State staff who worked to process financial eligibility applications and documentation stated that in cases where participants' assets and estate planning were not complicated, the application process typically took between 30 to 60 days. For participants who had complicated estate planning and large amounts of financial information to gather, the processing of an application could take up to 90 days or longer. The three-year look-back rule to determine financial eligibility was also noted as a challenge for financial eligibility staff and was seen as a stressful process for participants needing to gather large amounts of information about their assets. A particular challenge mentioned by financial eligibility staff was when family members or guardians (without full knowledge of a participant's financial situation) took on the responsibility for gathering the applicants' financial information, often prolonging the process significantly as they have to search for documentation that may be difficult to find or obtain from financial institutions.

"We hear this concern [the length of time it takes and amount of documentation required to process Medicaid eligibility] more from providers who want Medicaid granted so they can receive payment. In general, we have 30 days to process a Medicaid application, but long-term care applications often take longer due to the more complicated aspects of the rules and needing to deal with family members or other representatives who are often not familiar with the applicants' circumstances."

In cases where participants, family members, and/or guardians reported difficulties in gathering financial information, state staff stated that they offered to contact financial institutions to obtain financial documentation to help expedite applications.

"Generally it works fairly smoothly, but we've had to contact financial institutions and life insurance companies and annuity companies to get the ball rolling because power of attorney, or the spouse, or whoever is taking care of the application can't get the information we need...we will step up to the plate if we have to. We get probably a better response than they get, I'm not sure why."

A few state staff also reported that they found the financial eligibility process burdensome for many applicants and that it could also be emotionally

difficult as well. There were often fears from participants about losing their assets, e.g., their house and savings, during the financial eligibility process. Participants also often asked questions regarding financial responsibility, i.e., patient share costs, during the application process, as they were worried about out-of-pocket costs for their care. While state staff did not suggest particular concrete solutions to ease participant fears about out-of-pocket expenditures in the interviews, they did note this as a difficult process for participants.

Advocates: Eligibility Processes

In terms of program/clinical eligibility processes, some advocates noted that care plans were often based upon ILAs that might not represent a participants' changing needs over time. For example, they noted that assessments are to be performed annually but suggested they might not always be done in a timely manner to make real time changes in a person's plan of care. While case management regulations also require that reassessments be performed and care plans be modified, whenever a persons needs change, advocates also suggested that these reassessments may not always be performed in a timely manner either.

Some advocates went on to say that while the assessments are often a good reflection of a participant's functional needs, they may not always accurately reflect other needs, such as a person's ability to connect with his/her community. Consequently, service plans, based on assessments, may not reflect fully an individual's needs.

It really almost feels like they're experiencing static plans instead of a plan [of care] that is designed to help them move from where they were at a certain point to where they want to be. They may be addressing some health issues or some immediate long-term care supports, but some other broader issues about what they want to be in terms of life style and work and involvement in the community aren't always addressed."

Providers: Eligibility Processes

Most providers shared that they found the program/clinical eligibility process straight-forward. While they did not always agree with the number of hours or services granted, they did feel there was a fair amount of consistency statewide with how program/clinical eligibility was determined.

When speaking about financial eligibility processes, most providers found that this was a more time-consuming part of the eligibility process.

"The clinical side of this is fast and fair but then you have to wait forever for the financial approval or disapproval; sometimes that takes so long that the whole clinical assessment needs to be done over"

Another key theme related to financial eligibility, that some providers mentioned, regarded adult day services and rate-setting. Some providers stated that it was their understanding that a participant could not live in a nursing facility and attend an adult day program unless they or their family paid for the Adult Day services out-of-pocket. Additionally, it was their understanding that participants could live in ERCs and attend adult day programs, but the reimbursement rate for the community home or ERC was substantially reduced so much (by the adult day service rate) that the ERC could not afford to keep the participant as a resident. Because Medicaid regulations do prohibit payment for the same service to two providers, and ERC and nursing home rate-setting rates, a participant who wanted to continue attending a day program would need to file variances for day program services. Doing so requires knowledge and persistence on the part of the participant and provider. However, provider interviewees did not note how often variances were filed and whether participants had the knowledge to do so.

Participants: Impressions of Eligibility Processes

Participants who participated in interviews or focus groups and who seemed to understand the program, stated that the clinical eligibility process worked well and was fair. Participants noted that the financial eligibility piece was slow and confusing. Older participants were more likely to express embarrassment that they had not been able to find required paperwork or had not filled out the paperwork properly. Younger adults were more likely to express complaints or confusion about limits or rules regarding income, rather than assets. Some felt decisions had been made based on their income alone, others believed that spousal income was the determining factor, and those under 65 expressed the wish that they could be working and still be eligible for services.

Participants may still qualify for Medicaid, food stamps, or other assistance, even after starting work; however, participants may not have ample knowledge to access these services. Although employment programs and services such as food stamps are beyond the purview of CFC, additional assistance by CFC case managers to access these programs may increase some participants' ability to make connections to the community and access financial assistance to help defray living expenses.

Family Members: Eligibility Processes

Like participants, family members had very distinct views about clinical and financial eligibility. Most felt the clinical piece worked well and was fair, but the financial eligibility process was anxiety-provoking and difficult. In terms of clinical eligibility some family members suggested that the program did not completely provide for the needs of persons with dementia. They noted that supervision or cueing assistance of persons with dementia was not reflected in

their assessments, even though personal care needs were provided for in care plans.

On the financial eligibility side, many family members reported that they had the primary responsibility for filling out the paperwork to determine their family members financial eligibility. They noted that it could be anxiety-provoking and time-consuming to find the required documentation.

“For us the only real problem was that he was born in another country and we couldn’t find his citizenship papers. We didn’t have any money or a house so it was OK for us. My sister is going through the same thing right now but for her it is totally different, she can’t get any help because she still has money and she didn’t put their house in trust early enough so now she is afraid she is going to lose that too. She is at her wits end. I help as much as I can but I don’t drive and I’m not very strong. Mostly I just listen to her worries and that seems to help.”

Many family members also mentioned how useful it would be to have more accurate information about long-term financial planning earlier and more access to knowledgeable people for financial advice.

Choice and Preference of Settings and Services

The support to help participants express preferences and make choices within CFC was another topic area of the interviews and focus groups. Those interviewed were asked how much they felt CFC supported participants to voice choices and preferences for services and settings, what factors affected or supported participant decision-making, and what other suggestions interviewees had for supporting participants in their service and setting choices. Participants and family members were asked these same types of question but in terms of how they experienced choosing services and supports under CFC.

State Staff and Advocates: Choice and Preference

In terms of participant choice and preferences, state staff and advocates noted many of the same issues and therefore data from interviews with these two stakeholder groups are combined for this topic area. Quotes are labeled as either comments from state staff or advocates.

One theme that emerged for both stakeholder groups was that there were limitations at times in the range of choices in both setting and services. For example, in some regions of Vermont, the option of ERCs may not be available at a time when needed, because of a limited number of ERC providers. A few interviewees noted that if a setting option was not available when a participant wanted or needed it, then they viewed the CFC program as not offering equal

access across the state to all settings that CFC applicants and CFC participants may prefer.

“I think for this specific area...we only have 1 ERC and I really think that would...really be beneficial if we had more.”

- State Staff Interviewee

Another key theme that emerged from interviews regarding choice and preference was the recognition that there were many factors that affected participant decision-making. These included concerns about paying out-of-pocket for settings such as ERC's, the effect on decision-making while experiencing a medical crisis constituting a need for immediate care, and the effects of a cognitive impairment or dementia on a participant's decision-making.

“I don't think anyone would ever choose to go to the nursing home, given a choice...and what I mean by that is, people don't wake up one day and say 'Wouldn't it be great to go live in a nursing home.' I think it's more about, you know, here's my situation and how viable is it to really remain home or, you know, if I had an option to go live with another family than the nursing home, or go live with my own family and leave my house...you know, there are all sorts of factors. People don't want to be burdens, sometimes staff isn't available—there's all sorts of reasons why people would choose what they choose.”

-State Staff Interviewee

The role of others involved in supporting participants' choices and preferences was another focus in interviews with both state staff and advocates. Assistance to participants in making choices about their care was described in a number of ways by interviewees. Many state staff and advocates stated that they felt the case manager often had a key role in participant decision-making. In some cases, their case managers' involvement was viewed as having a positive impact on participant choice and preference. Some others remarked that case management involvement in decision-making could be improved by promoting person-centered planning to help participants further express their choices and preferences for services and settings under CFC.

“... in a good world we're trying to listen very hard to people...understand their wishes about staying home... how they feel about specific caregivers, how they feel about where they are. We're the ones that would figure out how to...effectuate what we understand somebody's personal preferences to be.”

-State Staff Interviewee

“I think it's a real strong Vermont thing [supporting people to make their own choices]...allowing people to live in different lifestyles.”

-State Staff Interviewee

“Even with the best of intentions and with really wonderful people doing case management, if the system is shaped that the case manager’s role is to manage a funding mechanism for providing a certain set of services to support long-term care, sometimes there isn’t enough time or focus on who is this person? and what are the life changes we need to address before you get into planning service dollar use? And so, you can manage the services, but sometimes the goals and issues that people with disabilities have about where they want to live or the barriers in the way to living more independently or dealing with some critical issues in their life, haven’t been grappled with.”

-Advocate Interviewee

Interviewees were asked what they felt could be improved to support participants to express choices and preferences. Some spoke of initiatives that had been started and others noted their own suggestions. For example, a few individuals spoke about starting care planning meetings at the agency level, which might serve as a forum where participants could voice preferences regarding their care. Others noted that a person-centered approach to care planning had been adopted by some agencies and could be adopted more widely to help support participants to voice their choices and preferences about care.

“I think that there’s probably a lot more that could be done. One of the things that we thought was important to kind of bring over from the [nursing] facility side to the community-based side, was giving people the opportunity to participate in basically a care plan meeting. We’ve been trying to do that on the Choices for Care home-based side because a lot of times other people were talking about the person; you know, the home health nurse, case managers to some extent, the doctor, social workers were all talking about what was going to happen to that person but they [the participant] weren’t involved in that discussion.”

-Advocate Interviewee

“In one of the programs, you know, we’re going to give 12 hours of case management and that’s what you get. Well, there are some people who need a little bit more, and there’s some people who might not need 12 hours...but we kinda say, well if you’re in this program [CFC] you get 12 hours. That’s not very person-centered...”

-State Staff Interviewee

The influence of others, such as family members and other providers (aside from case managers), on participant choice and preference was acknowledged by state staff and advocate interviewees as well. Some state staff and advocates noted that physicians’ and hospital discharge planners’ knowledge and attitudes about settings could affect participants’ choice of setting. Some noted that a lack of HCBS knowledge by physicians and their beliefs about HCBS effectiveness or availability, may lead to their advising

participants to choose nursing facility care. It was noted that nursing facility care may be the option doctors were most familiar with under CFC.

“Historically, there’s always been a problem that physicians and physician practices—which is often where the discussion of going into a nursing home happens—often don’t fully understand what the waiver offers and that it’s available, or some of the other resources that complement the waiver and so they may feel very strongly that the nursing home is the only place somebody should go. That really has a great weight on what people think are viable choices for them. That’s something that Vermont—both DAIL and providers and advocates—have been very aware of for years, is that you know, the importance of making physicians and the staff who work with them really more knowledgeable about what kind of home care and community services are available.”

-Advocate Interviewee

Many also stated that family members’ input and influence was also viewed as a barrier to participant decision-making, in some but not all cases.

“Families also sometimes have one set of expectations and one path they think the person should be taking, so they may only want information on a certain option, like, if they think a person needs to go to a nursing home then, we don’t need to know anything over here about home-based services. Sometimes that can be kind of a barrier to information getting really nicely to participants.”

-State Staff Interviewee

Providers: Choice and Preference

Many providers also spoke about the role of family and others in terms of influencing participant choices. In most cases, providers reported that when someone chose to move from one setting to another, it was their choice to do so but it almost never happened without some pressure from others as part of the process. Providers stated that family members and/or advocates were often the other parties involved in participants’ choice of settings. Providers noted that case managers struggled to balance respect for the choices of the participants with their own concerns about safety or the capacity of the family to care for the individual. In general, providers reported that participants’ did not often choose to move on their own but rather someone else made that choice for them. However, the providers said that the participants reportedly were often grateful afterwards.

“Here’s the real problem with Choices [for Care]. You can’t make an informed choice if you’ve never heard of something and you can’t really make it unless you’ve visited a place and talked to people, and found out what it is like. Most people have a pretty set notion that they want to stay home, they don’t want to change anything. So even though it [another setting] might be a better option, they won’t go.”

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Another challenge in supporting participant choice, noted by providers, was that access to certain settings and other geographical constraints made choosing a setting difficult for participants. These included choosing an option that meant being separated from family, familiar places and health care providers—not a good choice for many. Some providers felt these factors were consequently sometimes unavoidable because of the dispersed location of nursing facility beds or ERCs in the state. These issues will be discussed further in the Access section of this report.

Decisions about self-directed care, agency-based care, Flexible Options, and other ways of receiving services tended to reflect the desires and capacities of participants and their families, according to providers. It appeared that there was great flexibility in moving from one approach of service delivery to another. The role of the case manager was key in both decision-making and fine-tuning decisions about these services. On the contrary, individual caregivers noted that they were excluded from the decisions made by the care management teams regarding the CFC participant, even though they believe they possessed insights regarding participant preferences.

“They don’t ask me anything, they just tell me what they’ve decided when they’re done, but then she [the woman being cared for] and I talk it out and figure out how its really going to work.”

Participants: Choice and Preference

Almost all of the participant interviewees stated that they felt their preferences were honored and supported in developing a plan of services that would be best for them. They were particularly grateful for the way their case managers stayed in touch with them and tried to make changes to their services, if needed. Most participants using agency-directed or surrogate-directed care said that the case manager, their doctor, and sometimes specialists were the team that decided the parameters of their care. They stated that they felt respected but not particularly “in charge” of the process.

“They all ask me what I want, how things are going, what’s next. The trouble is you don’t know how to ask for what you want, if you don’t even know what you need.”

Those utilizing the self-directed care option noted a different experience in terms of choices and preferences. This group of participant interviewees noted that they enjoyed staying informed, researching the latest developments in the field, hiring and training their own caregivers, and being a central member of their care team. This group also expressed satisfaction with ARIS and had a very sophisticated knowledge of other available support services in the community. They were very interested in the development of the 24-hour option and were the

group most likely to have visited ERCs and nursing homes as they planned for their long-term care needs.

“I’m pretty mouthy so they always know what I want and usually, sooner or later they do it.”

Family Members: Choice and Preference

Overall, family members stated that CFC was a thoughtfully designed and flexible program in that it provided professional support for their family members’ needs. Some family members of CFC participants who had a case manager reported that they and the participant were satisfied with the case managers involvement in decision-making.

“There’s a lot of respect. It felt like we were all a team trying to figure out the best thing.”

However, many families expressed the fear that they themselves didn’t have enough knowledge or skill to help their family member in CFC make the best choices.

“You can’t ask for something you’ve never heard of.”

“I wish we had known more about it, what would really be involved, before we moved her home with us. Maybe they should have a training program before people make these decisions. What it’s really going to mean to help her go to the bathroom, take a shower, the physical parts: and about how exhausting it’s going to be. Sometimes I’d fall asleep at work.”

Access to Services

All interviewees were asked whether CFC provided access to services that were authorized in CFC participant care plans and whether they felt CFC was providing enough services to those choosing to live the community.

State Staff and Advocates: Access

The shortage of PCAs and LNAs was the issue most frequently cited both by state staff and advocates. They reported that participants were often not able to receive all the hours authorized in their care plans because there were often not enough workers to fill these hours, especially weekend and evening hours. Reasons suggested for the worker shortage (and retention) included low hourly wages for PCAs, no reimbursement for transportation costs, and inadequate training opportunities for direct care workers.³

³ Vermont’s legislature in collaboration with the long-term care community in Vermont, have established a taskforce to study work force issues and how they relate to gaps in care. Their

Transportation was another common theme cited by both state staff and advocates. Many noted that, in rural regions of Vermont, workers may have to travel long distances to reach participants' homes, without mileage reimbursement. In addition, the lack of reliable and adequate public transportation also made it difficult for participants to have access to other services, such as adult day programs. While Medicaid does pay for transportation to adult day program for those in the Highest and High need groups, transportation for this service remains a challenge for participants in the moderate needs group.

A third topic noted by state staff and advocates related to access, concerned the scope of services that CFC provided under the waiver. As mentioned above in reference to the ILA, CFC was seen by many interviewees as a program that supported ADL needs effectively; however, services such as companion and social supports were seen as lacking under the waiver. While CFC allow up to 720 hours per year for companion and respite services for those in the Highest and High needs groups, some state staff and advocates suggested that this may not be enough to support all participant needs or these hours may be under-utilized due to a lack of knowledge on the part of either providers or participants.

"We've come across a number of people who've asked to participate more in events outside of their home, whether that's visiting friends or as simple as going out to lunch. How do I get there? How do I—if I want to spend a day at the senior center, how do I get there? How can I make that happen? So I think there are things that people would like to see, and these are all things that the Choices for Care program could help people do. I think that there's certain aspects of it, and again, I think it's going to be more around those relationships/social things/community participation sorts of things where I think some of the providers have just not been used to that."

-State Staff Interviewee

State staff and advocates also reported that while CFC provided some hours for services for those with dementia and psychiatric disabilities (such as cueing and medication management), the level of these supports under the waiver was limited. Lastly, another concern related to access noted by a few state staff and advocates was the cap on CFC funding for home modifications, a service that could help a person remain in the community in the long-term.

January 2007 report focuses outlines the taskforces' study of the conditions and issues related to, and/or impact the quality, quantity, availability and stability of the direct care workforce.

“One of the areas that I feel is lacking that we struggle with [is] how to get accessible, affordable modifications for people’s houses. You may know that Choices for Care has a financial limit, so that can be a huge barrier for people that want to stay at home. How is that going to get paid for? Also, who has the know-how to do it? It [funding] varies. In Burlington, there’s actually quite a few sources of public funding for that...a lot of times you get a church or somebody willing to donate the labor; we just had somebody where the contractor’s association was willing...to put in accessible bathrooms for this person. The Centers for Independent Living have some resources, but it’s...definitely an area...a barrier.”

-State Staff Interviewee

Providers: Access

Many providers suggested that providing the kind of care that participants need and when it’s needed was a much greater access issue than obtaining approval for hours of care. A few agencies talked about the predicament of being unable to find qualified caregivers for approved hours of care, and having to deal with participants’ frustrations. Private caregivers mentioned that while they were generally happy to work flexible hours, they were increasingly unwilling to drive long distances because of the rising cost of gasoline.

“Let’s say you get approved for four hours of care a day because you need help with toileting and some other things. What do you suppose is the chance that someone is going to be there to help you when you actually need to go to the toilet? So you take the chance of falling and getting hurt and needing even more hours.”

Providers stated that few people were interested in caregiving due to poor pay, few benefits, and the tiring and dangerous aspects of the job. With high turnover rates, participants and their case managers had a difficult time finding workers for times when care is needed.

According to providers, the lack of access to transportation could also have quality of life repercussions for participants. Providers reported that they often would like to see participants with dementia and psychiatric disabilities have access to more stimulating social settings. This was an especially difficult situation in the rural areas of the state.

A final theme mentioned by some providers was that many of the preferred residential settings (such as ERCs) had waiting lists of at least two years, and some of the more remote rural communities have no ERCs. As a

result of this shortage, participants access to setting options can be limited in some areas of Vermont.

Participants: Access

The most critical access concern mentioned by most participants was the availability of skilled and consistent caregivers. This problem was identified across all participant sub-groups, such as people using agency-directed services, those self-directing, and those utilizing surrogate-directed care. Participants with agency workers mentioned experiencing high levels of uncertainty about when and if caregivers would show up and expressed frustration with the inability of many agencies to provide evening and weekend care. Those using self-directed and surrogate-directed care noted they had more control over these variables, though they did report it being more difficult to find satisfactory caregivers as first-time (or seasoned) employers.

“She’s been with me now for years. We get along really well and she’s willing to put up with me. She does just about everything, and she really knows how to do it. Before there must have been about a thousand people who wanted to work for me. They’d be there for about a week and next thing you know they’d be pregnant or needing to take care of their mother or something. It’s hard to find somebody as good and steady as she is. And here’s another thing. I think they need to get more training, get more education... They need to be paid more... And furthermore, they don’t get any holidays or sick time, if they don’t work, they don’t get paid. But for us [the participants] its better this way than with an agency because there, they just don’t show up and there’s not much you can do about it. It’s better if your name is on the paycheck.”

Like other stakeholder groups, participants also mentioned that they felt their choices were limited by geographic constraints. For example, a few participants noted that outside of certain counties, it was difficult to find a facility or community home that was close to family and had an opening. Having to move away from their home community and having to change doctors were frightening prospects for many participants. Some participants reported knowing that they would be safer in an alternate setting but felt they would be so unhappy having to give up their home that they would not consider moving.

As with other stakeholder groups, many participants noted the lack of transportation for non-medical needs. Those whose caregivers provided transportation express being especially fortunate and articulated the positive impact these caregivers had on their sense of well-being.

Family Members: Access

Limited service hours, lack of transportation, limited options for being meaningfully engaged in the community, and difficulty finding suitable caregivers were the most frequently mentioned access concerns of family members. Access to services was reported to be much easier in larger towns than for those living in rural areas.

In certain counties, the most difficult access issue for family members was the lack of suitable caregivers. Family members reported that if the caregiver hired to provide services for their family member worked for an agency, the participant seldom had care provided during evening hours or weekends. They noted that should the participant move to self-directed care, they would be challenged to pay a competitive rate and do their own advertising, recruitment, interviewing and training. A few family members said that the better caregivers were quickly recruited by the agencies where the pay and benefits, security, and hours were very appealing. Families said they often relied on teenage children living at home and other neighborhood children to meet critical needs. In addition, the need for CFC participant supervision was cited often by family members as an important need. For example, it was suggested that cueing and supervision needs in the cases of participants with dementia or cognitive impairments was even more critical than other services offered under CFC for some. A few families expressed interest in the new 24-hour option that they had heard some about, though none had any specific information about this option.

Many families felt that a combination of caring for the participant at home and having them attend a day program seemed a very good option under CFC. A few expressed distress that such programs could not be continued once participants moved into alternative residential settings such as ERCs or other congregate housing as discussed in the previous section of this report.

“This program is a godsend. He just about runs out of the house in the morning to get the bus [to the day program]. When it’s icy, that’s the problem. He’s not very steady on his feet and our driveway is too bad for them to get up. So he has to stay here and he gets depressed. And he usually takes it out on me. I know he doesn’t mean to, it’s just the disease, but it’s hard to take sometimes.”

Family members reported that medical transportation for appointments was usually accessible, but many spoke about the strain of having to pay for transportation to the day programs out-of-pocket. As noted above, CFC does offer transportation to day programs for those in the Highest and High needs groups; however, it is not offered for those in the moderate needs group although family member interviewees did not make this distinction. They did note transportation for day programs was a valuable service for the social and emotional well-being of their family members as well as their own ability to work.

Quality of Services

The questions regarding quality were, how well interviewees thought CFC services were meeting participants' personal care needs, whether services were helping participants go where they needed and wanted to go, to get around in the community and do what they would like to do in their free time. Interviewees were asked how they viewed the overall quality of CFC services for participants and if there were any particular groups within CFC for which service quality could be improved. While service access can be seen as relating to or affecting service quality or participant quality of life, it should be noted that data from these interviews do not represent a strict measurement of quality of services being delivered to all CFC participants.

State Staff and Advocates: Service Quality

State staff and advocates tended to answer these questions by relating quality to other aspects of services, such as access to services. Generally, state staff and advocates remarked that despite the issues related to access, the overall service quality was such that it met the basic needs of most CFC participants. A few noted that they felt the quality was good judging by the fact that there had been few ombudsman complaints in either nursing facilities or in HCBS settings regarding CFC services. A few respondents stated that while those who had more complicated needs might not have all their services met, the majority of participants have their basic needs met under CFC.

"I guess, you know, as we get out and look, I mean we're seeing some amazing services being provided, and providers going above and beyond and good, caring, compassionate people...almost at every agency that we go to we see that. ... In general, I think, you know, the provider community has really grasped the Choices for Care and what we want to do and providing people options, and I think they're doing a pretty good job of that. So, I guess I would rate the overall quality pretty high. The other piece of that is when we ask people directly, what do you think of your services? For the most part, we hear good, positive comments. There's always the, you know, even when, you know, is there things that you'd like to see different and people will say, well I'd really like to do this, I wish they would spend more time doing that. In general we're still hearing good positive comments about the services that people can get. So I'd say overall I think the Vermont community providers are really doing a good job."

-State Staff Interviewee

Other comments revealed some concerns related to service quality under CFC. As noted above, interviewees spoke about the limited access to some services which they viewed as affecting the quality of care under CFC. For example, interviewees suggested that the number of companion and respite hours (720 per year for those in the Highest and High groups) seemed limited which they viewed as restricting a participant's ability to connect with the

community and thus their quality of life. Approximately half of those state staff and advocates interviewed noted that changes in care plans could be requested, however, the approval of variances was determined on a case-by-case basis and obtaining a variance could vary from one region to another.

“I think informal supports are real important for some people to maintain them[selves] in the home. I can think of one situation that we’ve recently—client situation — we’ve recently had where the client is needing a lot of supervision-type things, more than the hands on, physical care. I think that’s harder to maintain that person with the number of hours that are warranted and so we look at those plans on an individual basis: can there be variances to any of the tasks to allow them more time? I think the supervision piece for some of the people with the dementia; it really needs to have the informal supports as well. It’s really very individualized [the number of hours provided for supervision] as far as what variance they’re asking for, and the case manager usually does a description of why the person needs more services and then we may talk about that and approve the ones that are reasonable ... In my area, I don’t receive a lot of variances—like this case I have—but there’s some other areas of the state I think you would get different answers because other places receive more variances than I do.”

-State Staff Interviewee

Coordination and communication between providers was also another theme state staff and advocates noted. Some stated that while case managers did communicate with LTCCCs and other waiver staff to some degree, interviewees said that increased communication among key service providers could lead to greater service quality for participants.

“In a perfect world, we would have those people [social workers and discharge planners] coming to participate in the waiver teams [meetings] so that they would know what’s going on in the program. We would have them communicate very closely with the case managers around standard discharges, and I think if they could step back and—both nursing home admission/discharge people and social workers—if they could just step back and understand that if they had a working relationship with those case managers out there their job would be easier.”

-State Staff Interviewee

Providers: Service Quality

In general, providers reported that the services available through CFC were of high quality. LTCCCs, case managers from HHAs and AAAs, residential facilities, congregate living settings, individual care homes, advocacy groups, adult day programs, the PACE program and most nursing homes were all given high marks by this group, as was ARIS by those for whom it was the payment

provider. However, these high marks were given in relation to protecting health and safety of participants. Only the adult day programs and a few of the smaller homes and congregate living settings were given high marks in terms of promoting social and emotional well-being or supporting family members. Some individual caregivers, case managers, nursing supervisors, and advocates were pointed out as providing exceptional emotional support for families. Most providers suggested that CFC did well to provide services within the home or other setting of choice, but less so with providing enough services to help participants connect with the community, despite companion and respite services.

Participants: Service Quality

Most participants' perception of the quality of services was closely tied to their personal relationships with caregivers and/or staff at agencies and facilities. Most participants were very pleased with the services offered by HHAs, COAs, senior centers or community homes, and advocacy organizations. They singled out individual caregivers, case managers, and advocates as being very helpful. People who were attending day programs, respite houses, and other community activities reported satisfaction with those services as well.

"We do a lot of laughing and singing, that's where most of my friends are."

Some participants living in alternative residential facilities were concerned about the level and training of the staff, saying that there just weren't enough people to do what needed to be done but that the attitude of staff made a critical difference. The greatest quality concern of those participants interviewed was regarding services provided in rehabilitation centers within nursing facilities where participants stayed for short-term rehabilitations.

"I used to be angry that they weren't more pleasant and cheerful. Then I thought, they don't want to be here any more than I do. So I started to joke with them about it, how we were all in the same cage, and we all started laughing and seeing each other as people more. Now, I listen to them and they all seem to like me and to go out of their way to keep me happy. I say attitude is the critical thing, the most important thing."

"They [rehab centers] are really unsafe, there isn't enough staff so when they need to go to the bathroom no one comes and then they try it themselves and fall, and then there's even less staff because they have to take care of the person that fell. I know it isn't their fault, it's just a money thing, they can't hire enough staff. But I sure was glad to get home."

Family Members: Service Quality

The actual assessment of quality of services by family members was based primarily on the individuals providing services. Family members expressed the most satisfaction with case managers, certain individual caregivers, day programs, and community homes. The strongest quality complaints expressed by family members were from those whose family member in CFC were living in nursing homes or small ERC's. They noted that there were often staffing shortages in these settings and therefore participants were not getting the attentive care they needed. They worried about social, emotional, and cognitive declines because there were not enough stimulating activities offered.

“Some of the girls we’ve had were really wonderful. They understood her even though she can’t talk and did all sorts of special things to help her self-esteem. When you find someone good, you have to worry that the agencies are going to hire them away from you, and you can’t blame them for going. We had one woman who was with us for years. She was creative and really connected with [the CFC participant]. I think they should hire someone like her and send her to school so that she can teach the others how to do this work well.”

Appeals and Ombudsman Processes

In terms of ombudsman services, interviewees were asked whether they had any concerns about CFC that resulted in complaints, the nature of the complaints, and whether and how the Ombudsman service helped to resolve those complaints.

State Staff: Ombudsman Services

Some state staff interviewees reported that complaints tended to be lodged at the provider level, at DAIL's Individual Support Unit and at times with the Quality Management Unit. Complaints logged at the service level tended to be resolved at the agency level; however, participants were also given information on Ombudsman services if they wanted additional help to resolve their complaint. A few interviewees noted that, in the first year of the CFC program, there was a small number of complaints relative to the number of CFC participants and an even smaller number of complaints in which the Ombudsman was involved.

When describing the kinds of complaints received, interviewees cited complaints regarding service hour authorization and financial eligibility. In some instances, an ombudsman was involved when complaints were heard by the Human Services Board. The general feedback from state staff was that Ombudsman services, when used, were helpful to resolve these types of complaints.

“The ombudsman here is very active and comes to waiver team meetings. I would say the cases where she has been involved in have been effective but I don’t think that we have had a whole lot [of cases where the Ombudsman was involved].”

State staff also outlined some challenges regarding the implementation of the ombudsman program. With the implementation of the CFC waiver, the ombudsman services were expanded to cover not only participants in nursing facilities but also to serve those receiving HCBS. Some state staff noted that the ombudsman program was understaffed, which made it difficult to serve participants in the community. A few state staff noted that it seemed easier for the ombudsman to reach those in nursing facilities because participants, family members, and providers are all on-site. Conversely, it was more difficult to reach people in the community with few ombudsman staff and a wider geographic area to cover.

Advocates: Ombudsman Services

Advocates commented on many of the same topics as state staff regarding the Ombudsman program. These included the value of the Ombudsman service to help resolve issues with the type and amount of services a participant receives, recognition of program challenges such as lack of Ombudsman staff, and the challenge to reach people in the community, given lack of staffing of the Ombudsman program.

Beyond these common themes, advocates noted that there seemed to be a lack of participant awareness about the Ombudsman service. A few commented that because of the challenge to reach more people in the community, the Ombudsman program had made connections with case managers to get the word out to participants about the Ombudsman program. Advocates saw this as augmenting the efforts by the Ombudsman to disseminate information to participants in the community and the information that CFC participants receive about Ombudsman services in their initial options education.

“I think what works well is to have a close relationship with the case managers. Because they [the Ombudsman] are not going into people’s homes on a regular basis like in the nursing homes, so we are really relying on the case managers to inform the participants about it [the Ombudsman program] and also have them contact us if they identify problems. In most cases we have a pretty good relationship with case managers”

Another aspect of participant lack of awareness in this area was a lack of knowledge about the appeals process regarding variances in service hours. One advocate noted that participants could benefit from more information about their rights to involve an Ombudsman or a Legal Aid to help appeal decisions when there were disagreements regarding the amount of services authorized as a

result of reassessments. While CFC regulations dictate that participants receive instructions on their rights to appeal services authorized in their care plans, advocates suggested that more clarity and more education around the appeal process would be necessary to improve participants' knowledge of their rights.

“Let me talk about one aspect first and that is how the reassessments are done. I think that they [participants] are not necessarily clear about their appeal rights and so once they get an assessment back and its been reduced [a reduction in services], I think there could be a little more clarity there and a little bit more knowledge that if they [participants] want to get their previous level of assistance that they need to appeal right away.”

Providers: Ombudsman Services

The majority of providers were aware of grievances procedures and the Ombudsman program. Many suggested that these were valuable services but also thought that they already have more informal—and usually more effective—ways of resolving complaints. If participants had a concern with their case manager, providers felt that participants were less certain about what to do. Based upon this data it suggests that many participant concerns are handled at the agency level by case managers however, participants could benefit from information about other services to help them resolve complaints should they have concerns that could not be resolved at an agency level.

Participants: Ombudsman Services

Most CFC participants reported that they were satisfied with their care and when they did have concerns participants reportedly either said nothing and figured time would fix it, or they talked to their case manager or an advocate to address the issue. A few participants interviewed, i.e., those who had lived in nursing homes or rehabilitation centers, were aware of the ombudsman program. Only two participants had experience with filing complaints through an Ombudsman. Both were living in facilities at the time they filed their complaints and had been released from the facility before resolving their complaint. A few participants mentioned changing agencies because they were unhappy with the lack of service they were receiving; however, these instances did not involve Ombudsman in order to do so. A few participants also reported switching from agency to self-directed care so that they could get what they needed more flexibly.

Family Members: Ombudsman Services

Most of the family members interviewed reported they were just so grateful to have help from service providers under CFC that they did not want to complain and noted that problems got solved on a personal level fairly quickly.

“When we have a problem we just call [the case manager] she takes care of everything.”

Some family members had heard about the Ombudsman program when their participant was in a rehabilitation center or a nursing home, but none had experience with seeking help from an Ombudsman. One family member who reported problems (regarding not enough service hours and the ARIS payment system) said

“I’ve been writing and calling and trying to get things straightened out. That’s why I agreed to do this [the focus group]. There are things that need to change but all you hear is: ‘Nothing can be done about it,’ or ‘that’s the regulation.’”

Another family caregiver reported making many calls complaining about the care her family member was receiving and that she felt that people began to ‘tune her out’. Neither of the family members who voiced their concerns during interviews was aware that the Ombudsman was available to participants utilizing the self-directed care option under CFC.

Other Cross-Cutting Themes from Interviews

A number of state staff and advocate interviewees spoke about the regional waiver team meetings in the course of their interview. Another theme that cut across interviews was the financial sustainability of the waiver, particularly with regards to the waiting list beginning in February 2008. While CHPR nor UVM interviewers specifically asked about these topics, data regarding these topics were of interest to report.

Waiver Team Meetings

State Staff and Advocates

A number of state staff and advocates mentioned the monthly waiver team meeting while answering questions during interviews (as seen in a few quotes in previous sections of this report). Respondents noted that the team meetings were a forum of LTCCCs, CFC providers, case managers from AAA’s and HHA’s, financial eligibility staff from DCF, Ombudsman, hospital discharge staff and at times, nursing facility staff. Interviewees remarked that the meetings were an opportunity to discuss new CFC applicants, issues relating to eligibility or services, and cases where an ombudsman was involved. Those who spoke about the waiver team meetings valued them as a way to communicate information about participants and applicants “since all the players are at the table”.

A few state staff/advocates suggested that increased attendance by nursing facility staff would be helpful when discussing applicants and current CFC participants.

“There are some people that do attend [waiver team meetings] on a regular basis – the home and community based case managers, discharge planners they are frequent but not at every meeting, DCF participates regularly ... We’d like to see more nursing home participation on the team and we have talked with our central office too about sending out something to all the nursing facilities about the team and the importance and what we can do for them, that kind of thing, that’s another work in progress”

-State Staff Interviewee

“The nursing home is a little different in that we don’t have an outside case management service for those folks because their services are all included and it also includes discharge planners and social workers. So it also does vary by provider how much they are helping someone [a participant] to access outside services. So we try to encourage those providers [from nursing homes] to come to multi-disciplinary teams that happen every month in all of our regions... I would say probably about half the nursing homes statewide attend their monthly waiver team meetings that are local to them... We are trying to think of creative ways to get them there [to waiver team meetings] and out of their day-to-day routine.”

-State Staff Interviewee

Financial Sustainability and Waiting List Activities

State Staff and Advocates

Some state staff focused on the waiting list that began February 2008 when they spoke about the financial sustainability for services under CFC. According to those interviewed, funding for the moderate needs group was also a concern. One state staff interviewed noted that the state might not be able to afford to run the waiver without a waiting list for an extended length of time. On the other hand, advocates expressed the need to ensure that HCBS receive continuous and adequate funding over time.

IV. Recommendations for Improvements

Interviewees shared a number of suggestions for improvements to the CFC program or suggestions on how to improve consumer care in general. There were several suggestions that were noted by multiple stakeholder groups interviewed from the data presented in the previous sections. For example, all five groups agreed that an increase in compensation for direct care workers

might serve to increase the supply of workers (such as PCAs) and could in turn improve the quality of care CFC participants receive. Table 5 shows all suggestions that cut across stakeholder groups. See Appendix 3 for recommendations or suggestions for improvements stated by individual interviewee groups (e.g. not noted by more than one group).

Table 5: Suggestions for Improvements to CFC across Stakeholder Groups

	State Staff	Advocates	Providers	Participants	Family Members
Increase pay and training for caregivers and direct care workers ⁴	✓	✓	✓	✓	✓
Make financial eligibility processes more timely and user-friendly	✓	✓			✓
Conduct more outreach to physicians ⁵	✓	✓			
Expand ongoing counseling of CFC services and settings (beyond options education)	✓				✓
Increase public education about LTC options including CFC	✓				✓
Subcontract with more providers to help with worker shortage	✓				✓
Offer additional funding for dentures	✓				✓

⁴ Specific recommendations included advancing the Vermont Association of Professional Care Providers (VAPCP) which may lead to more training opportunities for care workers.

⁵ Interviewees noted that physician outreach was conducted more at the beginning of CFC implementation and that more ongoing outreach would be helpful to continually educate physicians about CFC setting options and services.

V. Conclusions

Overall, each group of stakeholders interviewed shared generally positive impressions of the CFC waiver. However, as reported, interviewees also recognized that challenges and opportunities for improvements still existed within each issue area explored during the key informant interviews and focus groups. The following are further conclusions based upon interview information regarding the reported challenges to be considered as the CFC program implementation continues over the waiver's demonstration period.

Awareness

A key theme that emerged regarding awareness to CFC options was that while most stakeholders reported being aware of the basic service and setting options, knowledge of the newer options across all stakeholder groups could be improved. Many also noted that the case manager held a key role in the ongoing sharing of information to the participant, as their needs changed. Efforts to continue educating case managers about CFC services and settings, and particularly about the newer service options, would serve to help better inform participants. In addition, stressing the importance to case managers of continually educating participants could increase participant knowledge over time. Given that participants' needs change over time, which in turn constitutes a change in services or setting, continued education could better inform participants of their choices than initial options education could alone.

Eligibility

Regarding eligibility processes, interviewees reported that the most difficult piece for participants was the financial eligibility process. The three-year look back period was singled out as a particularly cumbersome process, especially for participants who had various or complicated assets. In those cases, this process could take up to 90 days due to the time it took to gather the necessary documentation. This could become even more challenging, as the look-back period will eventually change from three years to five years, as required by federal law. Interviewees expressed concern that the lengthy financial eligibility process created a delay in access to services due to the fact that not many CFC providers, with the exception of nursing facilities, were willing to presume financial eligibility. This could provide a subtle incentive for participants to choose nursing facilities over receiving care in the community. One suggestion was to formalize arrangements or to develop a best practice with HCBS providers so they could presume eligibility for participants while awaiting financial eligibility.

Generally, most stakeholders groups felt that the clinical eligibility process was efficient. However, some noted that the initial assessment tool itself (the ILA) and reassessments did not always accurately reflect participants' service needs

which was sometimes attributed to philosophical differences between case management agencies. Interviewees noted that AAA case managers tended to advocate more for participants in terms of services hours under CFC than case managers from HHAs. Some noted that HHA case managers tended to come from a medical model philosophy and were more concerned with how well services were meeting a participants' functional needs while AAAs advocated for services such as social supports and services that offered more connections to the community. Additionally, some noted that they felt the assessment was not designed to capture cognitive service needs as well as functional services needs.

Choice and Preference

While many interviewees reported that CFC participant preferences were generally supported, some noted that they viewed choice and preference as lacking due to factors such as participant lack of knowledge about options. Lack of knowledge was reported as hampering one's ability to adequately express preferences regarding services and settings of choice. As noted above continuing to have case managers educate CFC participants about their service options and setting options beyond options education could help foster more knowledge of services/settings and support participants to make informed choices about their care.

Another theme noted by many interviewees is that the full range of services is not often available to all CFC participants across the state, due to worker shortages and lack of ERCs and nursing home beds. Some argue that these shortages represent a lack of access to the full array of CFC services and thus limit choices to CFC participants and applicants.

Access

Access to PCA and LNA services⁶ was a key theme across most interviews when discussing access to CFC services. Many reported that there did not seem to be enough PCAs or LNAs to provide care for all the hours authorized in participants' care plans. Most stated that addressing the shortage of direct care workers to support CFC participants was the main area for improvement. Factors affecting this shortage included the lack of reimbursement for travel, low wages for many agency workers, lack of training, and lack of evening and weekend workers to cover participants' care needs. Efforts by the state, and by case managers to help increase the number of available caregivers have included creating a registry and looking at other community resources to help fill gaps in services. These efforts will be important to sustain to help address worker shortage issues.

Quality

⁶ Although LNA services are funded under the Vermont state plan and not under CFC, interviewees spoke about a lack of both PCAs and LNAs.

The overarching theme regarding quality of services was that the waiver provided adequate care for the basic functional needs of CFC participants, despite some of the issues related to access as summarized above. However, many interviewees saw room for improvement in terms of the scope of services provided by CFC. For example, many remarked that companion services could provide participants with more social support and connection to the community which could enhance quality of life. A few interviewees said that although many agencies were not able to provide social supports, state and local agencies were looking at creative ways for community organizations, such as churches and civic organizations, to help provide companion-like services to participants through volunteer work.

Ombudsman Services

Most interviewees who had experience with ombudsman services said that the program was helpful, particularly in cases where participants requested variances for service hours that had changed upon review of their assessment/reassessment. However, many noted that knowledge of the ombudsman for those receiving care in the community was limited, and that more awareness of the service would be helpful to participants. In addition, some interviewees stated that while the ombudsman service was valuable under CFC and that its expansion into community-based care was positive. The ombudsman staffing level posed a challenge to successful outreach to participants in the community. Appointing more staff could support Ombudsman efforts in the community and could increase the time spent educating participants about the services they offer.

General Comments about CFC

The overarching impressions of CFC services and general comments about the program were positive. A number of stakeholders acknowledged Vermont's continuing efforts to provide increasing access to home and community-based services through CFC and remarked that it had been successful in doing so. While many noted this they also recognized areas for improvement in order to continue to serve elders and persons with disabilities under CFC. As one individual noted, the waiver seems "progressive in its thought, [but] maybe not entirely in its application." This sentiment was indicative of stakeholders' acknowledgement of the CFC program as a positive step toward equal access to nursing facility and HCBS for elders and persons with physical disabilities. However, it also illustrates the recognition by stakeholders of the need for continuous improvements within the waiver.

Appendix 1

Interview Guide

Participant and Provider Awareness of Options

1. Have you had to explain some aspects of the Choices for Care (CFC) program to others?
 - a. If yes, to whom?
 - b. How have you explained the program?
 - c. Is there anything else consumers and providers should know about the program?
2. On average, about how many CFC participants does your agency serve per month?
3. How much do you know about these aspects of Choices for Care?

	A lot	Some	Very Little	None	Not sure
a. Services options by level of need					
b. Service settings					
c. Flexible Choices					
d. 24- hour care					
e. Option that pays a participants' spouse to provide help					

4. How did you learn about the CFC program?
5. In your experience, to what extent are the following groups generally aware of each of the options (3.a-3.e) of the CFC program?
 - a. NF staff?
 - b. Hospital charge planners?
 - c. Case management staff

- d. ERC staff?
 - e. Home health staff?
 - f. Adult day providers?
 - g. Participants?
 - h. PACE providers
 - i. Transportation providers
 - j. Family Members
 - k. Housing providers
 - l. Physicians
6. Have you observed that provider knowledge varied by:
- a. Provider type
 - b. Provider setting?
 - c. Other?
 - d. Please explain
7. How much do you think participant knowledge varies by:
- a. Region?
 - b. Participant's level of need?
 - c. Participant's service setting?
 - d. Please explain.
8. What opportunities/barriers do you think exist in informing participants about the program?
9. What opportunities/barriers do you think exist in informing providers about the program?
10. What could be done to ensure providers know all CFC service settings and options?
11. What could be done to ensure participants know all CFC service settings and options?

Eligibility Process and Procedures

12. Does your agency help the public apply for Choices for Care?
- a. If not, how familiar are you with this process of applying for Choices for Care?
 - b. How familiar are you with the criteria for the different "levels of need" in the program?
 - c. How familiar are you with the process of determining the wait-list and which wait-listed individuals are served?
13. To what extent do assessments reflect participants' needs? Please explain.
14. To what extent are you adequately supported to determine participants' level of needs for the program/financial eligibility? Please explain.
15. To what extent are case managers/NF social workers accurately re-assessing participants? Please explain.
16. How well is the process for determining whether participants are eligible to move from a community setting to a more restrictive setting, e.g., ERC, NF, 24-hour care?
- a. Does this process work consistently across locations? If not, why not?
 - b. What could help make this process better for participants?

Choice and Preference

17. To what extent do you think the Choices participants are supported to do the following:
(Please place “x” in the box that best describes your opinion. Please fill in who you think helps participants make choices about aspects of the program in the space provided. Please list all who apply.)

	A lot	Some	Very Little	None	Not sure
a. To choose the setting where they want to live, e.g., community, ERC, NF?					
a1. Who helps participants to choose where they want to live?					

	A lot	Some	Very Little	None	Not sure
b. To choose among available services?					
b1. Who helps participants to choose services?					

	A lot	Some	Very Little	None	Not sure
c. To choose whether to self-direct services?					
c1. Who helps participants to choose whether or not to self-direct their services?					

	A lot	Some	Very Little	None	Not sure
d. To choose their paid caregiver(s)?					
d1. Who helps participants to choose their paid caregivers?					

Access to Services

18. In your experience, how consistently are participants receiving all services authorized in their care plans? Why?

a. Can you think of specific ways to ensure that services are provided as authorized?

19. Do you think the Choices program is providing enough help to participants to live in the community?

a. If not, what supports or services do participants need that they are not receiving?

b. For whom is the program not providing enough help?

20. Have you interacted with participants' unpaid caregivers?

a. If yes, what role have they had?

b. For those participants, has their dependence on unpaid caregivers changed as a result of CFC? How?

21. Are you aware of any participants receiving services from other programs?

a. If yes, what programs? What services are they receiving?

Quality of Services

22. To what extent are CFC services helping participants to: *(Place "x" in the box that best describes your opinion)*

	A lot	Some	Very Little	None	Not sure
a. Meet their personal care needs?					
b. Go where they need and want to go?					
c. Get around in and outside the home?					
d. Do things they like to do in their free time?					
e. To what extent does this vary by location?					

22. Which participants are not able to have these needs met? Please explain.

23. How would you rate the overall quality of CFC services?

24. Could you suggest some specific ways to improve services for participants?

Appeals and HCBS Ombudsman Processes

25. Have you heard about any concerns regarding any aspect of the program?

- What kinds of concerns were raised? By whom?
- For participants, in what instances were ombudsman services used and in what instances were these services not used? Why/Why not?
- How effectively have concerns been addressed?
- Has this process varied by setting?
- What could improve the HCBS ombudsman service?
- What challenges, if any, has your unit encountered in responding to and resolving complaints?

Closing Question

26. Overall, how effective is the CFC program in supporting participants to live in the setting of their preference?

Appendix 2

Vermont Choices for Care Evaluation Interview Analysis

The codebook below lists all the interview topic areas (represented by codes 1000, 2000, 3000 and so on) and the themes within each topic area (represented by codes 1100, 1200, 2100, 2200 and so on). The descriptions in parentheses after some codes or themes are sub-themes encompassed within a particular theme. The numerical designations or codes served as a short-hand for themes for easier analysis of the data (interview summaries). These numbers do not indicate importance or frequency of themes found during analysis.

1000 *Awareness of Options*

- 1100** Awareness/understanding of new options & CFC processes around these new options
- 1200** Awareness/understanding of existing HCBS options & CFC processes
- 1300** Attitudes toward options/participants
- 1400** LTCCC options counseling (*includes amount of options counseling information*)

2000 *Eligibility*

- 2100** Support/facilitators (*case managers, DCF staff going above & beyond, etc.*)
- 2200** DCF staff's barriers/challenges (*i.e. process going over allotted 45 day period*)
- 2300** Participant burden/stress (*gathering information*)
- 2400** Accuracy/reliability (*coding mistakes, differences between CMs observing or asking, CM/LTCCC interaction, MH coding, CM turnover*)
- 2500** Comprehensiveness of assessment criteria (ILA) (*assessment doesn't include natural needs, social outcomes; too tied to ADL; should use tiers from ERCs; Access to cueing for MI/dementia*)
- 2600** Application process (*DCF staff knowledge, co-location challenges, participant knowledge, order of the application process/guidelines, delays in process*)
- 2700** Emotional Aspects of Financial Eligibility Process (*emotional process for applicants, fear about losing assets e.g. home*)

3000 *Choice and Preference*

- 3100** Range of CFC Choices (*geographic/service limitations, shortage/availability of workers, Other non-CFC services, too many service choices, shortage of ERC/NF bed in many regions*)

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- 3200** Assistance to Make Choices and Preferences (*CM role to help make decisions, help to find/identify a surrogate, care planning meetings, flyers about choosing CM agency, person-centered care planning, CM continuous options counseling based upon participant readiness for a service*)
- 3300** Participant Decision Making (*private pay considerations [i.e. ERC expenses], participant pre-conceived notions/decisions regarding services and settings, crisis decision making, cognitive impairment effects choice and preference*)
- 3400** Others' Influences on Choice and Preferences (*family influence, physician influence/knowledge, CM/discharge planner/other providers knowledge and attitudes about services and setting, Provider attitudes about SD-CD and Flexible Choices, provider guidelines about their role in helping participants with choices/preference*)
- 4000** Access
 - 4100** Limited amount of hours/funding (*limited companion hours, limited number of defined service hours (6 max), limited hours to serve more people, limited assistance from FI (ARIS) to self direct, adequacy of reimbursement of caregivers e.g. low hourly wages, no \$ for transportation*)
 - 4200** Limited scope of services
 - 4300** Low service utilization
 - 4400** Provider capability/capacity (*HHA regulations-refusal to serve people, CM know how lack of evening/weekend help/hours/lack of PCA/other workers, limited number of ERCs*)
 - 4500** Geographic barriers (*transportation, rural regions*)
- 5000** Quality of Services
 - 5100** Varying quality of services (*quality of social support services relative to PCA services, variation by region*)
 - 5200** Adequacy of service quantity (*limited companion hours, medication management*)
 - 5300** Coordination of providers regarding services for participants
 - 5400** Unmet needs by participant characteristics (*more medical needs=more unmet needs*)
 - 5500** Positive perception of service quality (*higher quality PCA services, generally serving most well, caregiver attentive to client's needs, fewer complaints*)
- 6000** Ombudsman/Complaints
 - 6100** Value of ombudsman services (*variances, family conflicts*)

6200 Implementation challenges (*few ombudsman/many HCBS consumers, process easier in NF*)

6300 Lack of awareness (*outreach difficult in rural areas, HCBS education challenging, participants aren't very aware of Ombudsman outside NFs*)

7000 *Cross-Cutting Themes*

7100 Waiver team meetings

7200 Financial sustainability of the waiver

7300 Other ideas for improvement

7400 General perceptions of CFC

Appendix 3

Suggestions for Improvement by Individual Stakeholder Groups

State Staff Suggestions for Improvements

Awareness of CFC Services and Settings

- Increase education to :
 - providers about CFC services (perhaps via online trainings).

Service and Provider Improvements

- Increase funding for:
 - home modifications under CFC or provide additional support to coordinate with other programs/services offering monies for home modifications.
 - transitional assistance for those transitioning from nursing facilities to the community,
- Address limited service hours for persons with mental illness and physical problems, and individuals needing cueing due to dementia,
- Increase access to ERCs and the 24-hour care homes by expanding these setting options around Vermont via state and provider collaboration,

Financial Eligibility/Other Financial Issues

- Work with federal lawmakers to re-evaluate financial eligibility rules that leave limited funds for participants to live on, and to clarify rules about how much participants are allowed under the Institutional Income Standard
- Simplify financial eligibility processes with participants by clarifying required documentation needed for the look-back period, possibly prioritize documentation for financial eligibility determination, i.e., collecting some documents later in the process.

Clinical Eligibility Processes

- Increase the number of LTCCCs
- Shorten the ILA assessment tool to help to expedite the clinical assessment process.

Other CFC Program Improvements

- Increase communication among providers.
- Provide a service to help self-directing participants to hire, train and fire workers.
- Adopt a more person-centered approach to care planning and CFC service delivery under CFC.

Advocates Suggestions for Improvements

Awareness of CFC Services and Settings

- Increase ongoing education of participants by the LTCCCs, beyond the initial sheet participants are given, about Ombudsman services at options education.

Financial Eligibility/Other Financial Issues

- Develop presumptive financial eligibility

Clinical Eligibility Processes

- Expedite the re-assessment process so that participants' changing needs are reflected in their care plans and services.
- Disclose to participants, advocates, or providers criteria used when LTCCCs determine service hours from the ILA

CFC Coordination with Other Programs

- Coordinate peer education and formal trainings for those CFC participants who are self-directing to increase skills on hiring and firing workers.
- Coordinate with other state entities to learn of ways to increase the capacity of communities to provide additional transportation.
- Coordinate with other programs to learn about other alternatives for senior housing options and to increase awareness of other living options.

Providers Suggestions for Improvements

Awareness of CFC Services and Settings

- Improve the continuous education of participants beyond options education
- Educate participants on newer CFC options

Service and Provider Improvements

- Provide more social and emotional supports to participants through CFC services.
- Offer more emotional supports such as respite for caregivers in rural communities, including those in the moderate needs group.

Choices and Preference Improvements

- Allow time and information to enable participants to make real informed choices and learn about the real options by visiting settings.

Financial Eligibility Processes

- Consider having the same people at the state do financial and clinical eligibility in order to speed up the decision-making processes regarding financial eligibility.
- For those participants in PACE, use the same eligibility forms to help eliminate confusion for financial eligibility processes.

Other CFC Program Improvements

- Rename the moderate needs group because there are often people with various levels of need in this group.
- Encourage CFC provider associations and independent providers to create a forum for mutual learning.

Participants Suggestions for Improvements

Service and Provider Improvements

- Fund more durable medical equipment and other assistive technologies that improve independence for all, including the moderate needs group (new wheelchairs, walk-in bath tubs, and other assistive devices).
- Contract for more ERCs in rural communities.
- Assure adequate staffing to fill authorized service hours.

Financial Eligibility Processes

- Change the policies so that all have access to long-term care and keep their homes.

CFC Coordination with Other Programs

- Encourage participants to form peer groups.
- Allow continuation of Section 8 or food stamps for incomes higher than the current limit
- Encourage case managers to help participants to connect to other programs that provide access education opportunities, e.g., Vermont Student Assistance Corporation (VSAC).

Family Members Suggestions for Improvements

Awareness of CFC Services and Settings

- Provide education and information to the general public about long-term care issues early and often including options under CFC (apart from information given at options counseling).

Service and Provider Improvements

- Have case managers provide ongoing information about Flexible Choices and the 24-hour care pilot option
- Increase training opportunities and respite for family caregivers whose participants are in the Highest and High need groups.
- Provide a forum for family caregivers to come together regularly so that they could share information with one another.

Choices and Preference Improvements

- Provide an orientation for family caregivers before they made decisions regarding their family member's care.

Clinical Eligibility Processes

- Revise the ILA so that it better reflects the needs of persons with dementia.
- Modify the ILA so that it more accurately reflects the actual capacity of the family to provide care.

Other CFC Program Improvements

- Provide access to long-term care financial planning, e.g., through consultations with a long-term care lawyer

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